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14. ABSTRACT

Purpose: Youth with special health care needs (YSHCN) encounter unique challenges in the transition from pediatric to adult healthcare. Although discussing transition with healthcare providers can be beneficial, it is unclear whether the providers' scope of practice (child-only vs. lifespan-oriented) drives these discussions. We examined the association between scope of practice and transition-related services. **Methods:** We used caregivers' responses in the 2005–2006 National Survey of Children with Special Healthcare Needs. We compared transition outcomes for youth whose providers treated only children, and youth whose providers also treated adults (lifespan-oriented). Individual and household-level demographic factors were applied to logistic regression models.

Results: Youth with lifespan-oriented providers were more likely than youth with child-only providers to have discussed changing health needs in adulthood (52% vs. 43%) and adult health insurance (24% vs. 21%). There was no difference in receiving encouragement toward self-responsibility (79% vs. 78%). These associations persisted after adjusting for demographics.

Conclusions: YSHCN are more likely to report having discussed issues related to transition into adult healthcare if their providers treat adults as well as children. However, discussion involving adult health insurance in particular was lacking for all YSHCN.

15. SUBJECT TERMS

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Association of Provider Scope of Practice With Successful Transition for Youth With Special Health Care Needs

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Keywords: Adolescent, Disabled children, Child health services, Delivery of health care, Health care surveys, Health planning, Health services needs and demand

ABSTRACT

Purpose: Youth with special health care needs (YSHCN) encounter unique challenges in the transition from pediatric to adult healthcare. Although discussing transition with healthcare providers can be beneficial, it is unclear whether the providers' scope of practice (child-only vs. lifespan-oriented) drives these discussions. We examined the association between scope of practice and transition-related services.

Methods: We used caregivers' responses in the 2005–2006 National Survey of Children with Special Health-care Needs. We compared transition outcomes for youth whose providers treated only children, and youth whose providers also treated adults (lifespan-oriented). Individual and household-level demographic factors were applied to logistic regression models.

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Conclusions: YSHCN are more likely to report having discussed issues related to transition into adult healthcare if their providers treat adults as well as children. However, discussion involving adult health insurance in particular was lacking for all YSHCN.

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Youth with special health care needs (YSHCN) are those who have, or are at an increased risk of a chronic physical, developmental, behavioral, or emotional condition, and who also require health services beyond that required by youth in general [1]. Transition, the process of moving from child- to adult-oriented health care [2], is critical for YSHCN. However, most YSHCN do not receive adequate guidance to help them navigate the process of transition [1,3]. Providers such as family physicians or those

dually trained in internal medicine and pediatrics, hereafter termed as "lifespan-oriented providers," may be uniquely equipped to provide effective transition care. The objective of this study was to determine the association between provider scope of practice and receipt of transition-related services for YSHCN.

Methods

We analyzed the responses of caregivers in the 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). Details of the sampling and collection methods have been described elsewhere [4]. Our sample was limited to children aged 12–17 years.

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The independent variable was "scope of practice of the health care provider." This variable was derived from one of the four questions in the *Transition Issues* section of the NS-CSHCN, "Do any of your child's doctors or other health care providers treat only children?" A "yes" response categorized that child's provider(s) as *child-only*, whereas a "no" categorized the adolescent's provider(s) as *lifespan-oriented*.

Three dependent variables were chosen from the remaining questions in the *Transition Issues* section of the NS-CSHCN: (1) "Have your child's doctors or other health care providers talked with you or your child about his/her health care needs as he/she becomes an adult?"; (2) "Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?"; and (3) "How often do your child's doctors or other health care providers encourage him/her to take responsibility for his/her health care needs, such as taking medication, understanding his/her diagnosis, or following medical advice?".

We used child's age, gender, race/ethnicity, health insurance coverage at the time of interview, functional limitation, household income, and parental education as covariates. Age was used as a continuous variable in the multivariate model.

Statistical analysis

We used the sampling weights of the NS-CSHCN for analysis. We used Pearson's Chi-square tests for bivariate analyses and logistic regression models for multivariate analyses. A *p* value of <.05 was considered statistically significant. All analyses were conducted using Stata version 10.1 (Statacorp, College Station, TX). The protocol was reviewed by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Results

A total of 18,198 YSHCN aged 12–17 were identified (Table 1). Of these, 39% received care from a lifespan-oriented provider and 61% received care from child-only providers. YSHCN with lifespan-oriented providers were older, more likely to be female, non-Hispanic white, and less likely to have severe functional limitation.

Transition related care

Discussions regarding changing health needs in adulthood, adult health insurance, and taking responsibility in managing healthcare needs were reported by 46%, 21%, and 78%, respectively. Older youth were more likely to receive transition services than their counterpart. Discussion of adult health needs was more common for female, non-Hispanic, and insured YSHCN. Non-Hispanic black and insured YSHCN were more likely to have discussed health insurance. Encouragement of responsibility for healthcare was more likely for female and insured YSHCN (Table 2).

Discussion of adult health needs was more common with lifespan-oriented providers (52% vs. 43%; p < .01), as was discussing adult health insurance (24% vs. 21%; p < .01). Encouragement of responsibility for health care did not differ by provider type (79% vs. 78%; p = .30). Multivariate modeling showed that adolescents with lifespan-oriented providers had significantly higher odds of having discussed adult health needs (adjusted Odds Ratio [aOR]: 1.35, 95% Confidence interval [CI]: 1.16–1.57) or adult health insurance (aOR: 1.24, 95% CI: 1.04–1.48), ad-

Table 1 Characteristics of sample (weighted) (n = 18,198)

Characteristic	Total sample	Lifespan- oriented providers	Children- only providers	p-value between subgroups
Age, years (mean)	14.5	14.7	14.3	<.01
Age (%)	50	42	E 4	- 01
12–14 years	50	43	54	<.01
15–17 years	50	57	46	0.4
Sex (% male)	57	55	58	.04
Race/Ethnicity (%)				
Non-Hispanic white	68	72	67	<.01
Non-Hispanic black	16	13	17	
Hispanic	10	10	11	
Other	6	6	6	
Parental education (%)				
Less than high school	6	6	6	.79
High school graduate	17	17	17	
Beyond high school	78	77	78	
Household income	11	12	11	.37
(% at or below FPL)				
Health insurance (%)				
Private	62	61	63	<.01
Public	25	26	25	
Private and public	7	6	7	
Other	2	2	2	
Uninsured	4	5	3	
Functional limitation (%)				
None	36	36	37	.03
Mild	39	41	38	
Severe	25	23	25	

FPL = federal poverty level.

justed for covariates. There was no difference in encouragement toward self-responsibility (aOR: 1.13, 95% CI: .92–1.38).

Discussion

For YSHCN, the presence of a lifespan-oriented provider as part of the overall healthcare team significantly increases the likelihood of having discussions salient to transition. Prior studies have identified both adult providers' lack of knowledge and skills to treat YSHCN [5,6] and pediatricians' lack of skills in transitioning YSHCN to adult healthcare [7–9]. Our study suggests that lifespan-oriented providers, when compared with child-only providers, are more likely to facilitate the transition care of YSHCN.

Pediatric-specific providers may find the experiences, clinical support systems, and resources of lifespan-oriented providers to be valuable in optimizing transition for their patients. For lifespan-oriented providers, the ongoing challenge of continuing effective transition care to YSHCN should serve as an affirmation of and a call to greater consideration of the life course approach to primary care [10]. The life course paradigm inherently considers the links between early life events and often-distant sequelae, rendering it likely a highly useful approach to care of YSHCN. The associations we observed between sociodemographic factors and transition outcomes are consistent with those reported previously.

Limitations of this study include the low response rate (56%) for the NS-CSHCN and use of parents as respondents. The accuracy of parental report for type of provider has not been determined. Provider-type definitions are constrained by the wording of the questions in the NS-CSHCN. Provider characteristics or demographics are not available in the NS-CSHCN to evaluate

Table 2 YSHCN characteristics associated with transition

YSHCN characteristic	% discussing adult health	<i>p</i> -value	% discussing adult insurance	<i>p</i> -value	% encouraged in self-responsibility for health	<i>p</i> -value
Total sample	46	_	21	_	78	_
Provider type						
Child-only	43	<.01	20	<.01	78	.30
Lifespan-oriented	52		24		79	
Age						
12-14 years	44	<.01	18	<.01	76	<.01
15–17 years	48		25		80	
Sex						
Female	52	<.01	22	.31	74	<.01
Male	42		21		70	
Race/Ethnicity						
Non-Hispanic white	47	<.01	21	<.01	81	<.01
Non-Hispanic black	39		19		70	
Hispanic	48		26		74	
Other	51		21		74	
Parental education						
Less than high school	45	.37	22	.72	69	.66
High school graduate	49		22		71	
Beyond high school	46		21		72	
Household income						
≤100% FPL	48	.42	22	.55	72	.80
>100% FPL	46		20		71	
Health insurance						
Private	47	<.01	21	<.01	75	<.01
Public	45		21		67	
Private and public	53		28		64	
Other	40		15		71	
Uninsured	38		16		59	
Functional limitation						
None	46	.20	22	.59	86	<.01
Mild	47		21		79	
Severe	44		21		65	

FPL = federal poverty level; YSHCN = youth with special health care needs.

provider-level factors. Finally, the cross-sectional nature of the study precludes assessment of causality.

Our study results suggest that training regarding insurance for YSHCN should be encouraged for all healthcare providers. Longitudinal studies examining the effectiveness of the transition process on health outcomes are needed. Future research should also consider the effect of training healthcare providers on transition care, explore the effect of provider discipline and specialty on approaches to transition planning, and identify optimal models to prepare adolescents for transition.

Conclusion

Although improving the quality of transition care for YSHCN will not be solved with a simple intervention, our study suggests that lifespan-oriented providers and a life course approach may be critical components to improve transition and overall health for these adolescents.

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